

NATIONAL CARERS CONFERENCE

TUESDAY 18 NOVEMBER 2014

KEEPING CARERS CONNECTED CONFERENCE

GOLD COAST

GLENN REES AM

CHIEF EXECUTIVE OFFICER

ALZHEIMER'S AUSTRALIA

IMPROVING SUPPORT FOR CARERS

THANK YOU TO CARERS AUSTRALIA FOR INVITING ME TO THIS CONFERENCE AND FOR THE OPPORUNITY TO PARTICIPATE IN THIS PANEL DISCUSSION.

YOU HAVE BEEN PRIVY TO A BROAD RANGE OF INTERESTING PRESENTATIONS AND DISCUSSIONS OVER THE LAST 3 DAYS AND I WOULD NOW LIKE TO SHIFT THE FOCUS ONTO HOW WE CAN IMPROVE SUPPORTS FOR CARERS OF PEOPLE WITH DEMENTIA.

THERE ARE MORE THAN 320,000 AUSTRALIANS LIVING WITH DEMENTIA AND IT IS ESTMATED THAT THERE ARE APPROXIMATELY 1.2 MILLION AUSTRALIANS INVOLVED IN PROVIDING CARE IN SOME WAY.

70% OF PEOPLE WITH DEMENTIA ARE LIVING IN THE COMMUNITY. MANY OF THESE PEOPLE ARE ACCESSING FORMAL SERVICES BUT IT IS CLEAR THAT WITHOUT THE SUPPORT OF INFORMAL CARE, MANY MORE WOULD NEED TO BE LIVING IN RESIDENTIAL AGED CARE.

IN 2010 IT WAS ESTIMATED THAT PEOPLE WITH DEMENTIA RECEIVED 210 MILLION HOURS OF INFORMAL CARE IN AUSTRALIA.

CARING FOR A PERSON WITH DEMENTIA BRINGS WITH IT A RANGE OF CHALLENGES IN PART BECAUSE OF THE PROGRESSIVE AND AT TIMES UNPREDICTABLE NATURE OF THE DISEASE. A CARER IS OFTEN COPING WITH SIGNIFICANT GRIEF AT THE SAME TIME THEY ARE TRYING TO RESPOND TO CHANGING BEHAVIOURS AND SYMPTOMS. CARING RESPONSIBILITIES CAN HAVE AN IMPACT ON PEOPLES HEALTH, WELLBEING AND FINANCIAL STABILITY.

A RECENT STUDY BY SIOBHAN O'DWYER AT GRIFFITH UNIVERSITY FOUND THAT APPROXIMATELY 1 IN 4 CARERS OF PEOPLE WITH DEMENTIA HAD CONTEMPLATED SUICIDE OVER THE PAST 12 MONTHS.

GIVEN THE LARGE NUMBER OF PEOPLE INVOLVED IN PROVIDING CARE TO PEOPLE WITH DEMENTIA AND THE IMPACT, BOTH POSITIVE AND NEGATIVE, THAT IT CAN HAVE, IT IS ESSENTIAL THAT WE CONSIDER HOW TO BETTER SUPPORT CARERS.

I HAVE TALKED WITH MANY CARERS DURING MY TIME AS CEO OF ALZHIEMER'S AUSTRALIA. I FIND OVERWHEMLINGLY THAT THE BIGGEST FRUSTRATION IS THAT OFTEN WHEN THEY REACH OUT FOR FORMAL SERVICES OR SUPPORTS THEY SIMPLY CAN NOT GET ACCESS TO APPROPRIATE CARE WHETHER IT BE RESPITE, AGED CARE SERVICES, OR HOSPITAL CARE. ACCESS TO SERVICES IS PARTICULARLY DIFFICULT FOR PEOPLE WITH YOUNGER ONSET DEMENTIA AND FOR THOSE WHO EXPERIENCE BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD).

AT TIMES CARERS ALSO STRUGGLE IN KNOWING HOW BEST TO RESPOND TO DIFFICULT ISSUES AROUND BEHAVIOURAL SYMPTOMS SUCH AS AGRESSION AND DISINHIBITION.

SO THE THREE MAIN ISSUES I WANT TO CONSIDER TODAY ARE:

- HOW TO GET THE BASICS RIGHT?
- HOW CAN WE PROMOTE BETTER ACCESS TO RESPITE SERVICES AND SUPPORTS FOR PEOPLE WITH DEMENTIA AND THEIR CARERS?

- WHAT SPECIALIST SERVICES DO WE NEED TO BUILD CAPACITY IN CARERS TO ASSIST THEM IN PROVIDING SUPPORT TO PEOPLE WITH DEMENTIA?

GETTING THE BASICS RIGHT

IN THE EARLY 1980S CARERS FORMED ALZHEIMER'S ORGANISATIONS ACROSS AUSTRALIA TO PROMOTE ACCESS TO INFORMATION, SUPPORT, EDUCATION AND SERVICES. SINCE THAT TIME THE ORGANISATION HAS BECOME INCLUSIVE OF PEOPLE WITH DEMENTIA BUT THE CORE EXPECTATIONS OF CARERS REMAIN MUCH THE SAME AND ARE CORE ACTIVITIES OF ALZHEIMER'S ORGANISATIONS.

THE RECOMMENDATIONS MADE BY THE PRODUCTIVITY COMMISSIONS REMINDED US THAT THERE HAS BEEN COLLECTIVE FAILURE IN INFORMATION PROVISION. THE MY AGED CARE CONTACT CENTRE AND NEW ASSESSMENT SERVICES WILL HOPEFULLY DO A BETTER JOB BUT ALZHEIMER'S AUSTRALIA HAS CONCERNS THAT NOT ENOUGH ATTENTION HAS BEEN GIVEN TO THE SPECIAL NEEDS OF PEOPLE WITH DEMENTIA AND THEIR CARERS.

FOR THOSE WHO ARE SOCIALLY ISOLATED AND ARE DISADVANTAGED AND UNLIKELY TO TRUST MAINSTREAM ORGANISATIONS THERE IS A NEED FOR EXTRA SUPPORT AND NETWORKING WITH ORGANISATIONS THAT UNDERSTAND THE NEEDS OF PARTICULAR GROUPS THAT HAVE DIVERSE NEEDS.

FAMILY CARERS HAVE CALLED FOR MANY YEARS FOR DEMENTIA KEY WORKERS WHO CAN ASSIST PEOPLE WITH DEMENTIA AND THEIR FAMILY CARERS TO ACCESS INFORMATION AND SERVICES AS NEEDS CHANGE, TO IDENTIFY SERVICE GAPS AND WORK WITH PROVIDERS TO DEVELOP NEW SERVICES. WE NOW HAVE THAT CAPACITY IN YOUNGER ONSET KEYWORKERS AND THE ASPIRATION IS TO

EXPAND THE FUNCTION TO PEOPLE OF ALL AGES STARTING WITH THOSE WHO ARE SOCIALLY DISADVANTAGED.

AND OF COURSE CARERS NEED TRANSPARENT INFORMATION ON CARE OUTCOMES THROUGH QUALITY INDICATORS AND RESIDENT'S SURVEYS SO THAT CARERS CAN MAKE INFORMED JUDGEMENTS ABOUT THE SERVICES THAT WOULD BE BEST TO MEET THE NEEDS OF THE PERSON THEY CARE FOR.

ACCESS TO RESPITE SERVICES

REGARDLESS OF THE SYMPTOMS ASSOCIATED WITH DEMENTIA, MOST CARERS VALUE RESPITE AS ONE OF THE MOST IMPORTANT SERVICES THAT SUPPORTS THEM TO CONTINUE TO PROVIDE CARE AND SUPPORT.

YET ACCESS TO RESPITE CAN BE VERY DIFFICULT.

IN THE MOST RECENT SURVEY OF DISABILITY AND CARERS, 48% OF PRIMARY CARERS OF PEOPLE WITH DEMENTIA REPORTED RESPITE CARE AS THEIR MAIN UNMET NEED COMPARED TO 15% OF ALL OTHER PRIMARY CARERS.

THE REASONS FOR CARERS NOT USING RESPITE SERVICES ARE COMPLEX BUT SOME OF THE ISSUES THAT CONTRIBUTE INCLUDE INFLEXIBILITY OF RESPITE CARE, SERVICES NOT AVAILABLE WHEN REQUIRED, LITTLE PERCEIVED BENEFIT TO THE PERSON WITH DEMENTIA AND SERVICE PROVIDERS LACKING THE EDUCATION AND TRAINING TO EFFECTIVELY MANAGE BPSD MAY ALL PLAY A ROLE.

THERE ARE TWO MAIN APPROACHES TO TACKLING THESE BARRIERS TO RESPITE USE. FIRST THERE IS A NEED TO DEVELOP THE SERVICE INFRASTRUCTURE TO ENSURE THAT RESPITE SERVICES ARE ABLE TO SUPPORT PEOPLE WITH

DEMENTIA INCLUDING THOSE WITH HIGH CARE NEEDS. THIS INCLUDES ENSURING ADEQUATE TRAINING AND INFORMATION FOR STAFF AS WELL AS ADEQUATE RESOURCING OF THE SERVICES. ALZHEIMER'S AUSTRALIA HAS BEEN ADVOCATING FOR A DEMENTIA SUPPLEMENT WITHIN RESPITE SIMILAR TO THE SUPPLEMENT PROVIDED IN COMMUNITY CARE.

SECONDLY, ALZHEIMER'S AUSTRALIA HAS BEEN ADVOCATING FOR A TRIAL OF A MORE FLEXIBLE APPROACH TO RESPITE THAT INCLUDES CASHING OUT OF THE BENEFIT. THIS WOULD POTENTIALLY ENABLE CARERS TO EMPLOY FAMILIES OR FRIENDS TO ASSIST IN PROVIDING RESPITE WHEN IT IS NEEDED. THERE ARE A RANGE OF ISSUES THAT NEED TO BE EXPLORED AROUND BENEFITS, RISKS AND IMPACT ON WORKFORCE - BUT THIS CAN ONLY BE DONE THROUGH A CAREFULLY EVALUATED PILOT OF THIS APPROACH.

A SURVEY OF FAMILY CARERS CONDUCTED BY ALZHEIMER'S AUSTRALIA IN 2012 FOUND THAT 50% OF RESPONDENTS WOULD TAKE UP AN OPTION OF "CASHING OUT" FOR RESPITE SERVICES IF IT WAS AVAILABLE. MANY CONSUMERS FELT THAT THIS OPTION WOULD BE MORE FLEXIBLE, EASIER TO ARRANGE AND THE PERSON ENGAGED TO PROVIDE CARE WOULD BE KNOWN TO THE CARER AND CARE RECIPIENT AND FAMILIAR WITH THEIR NEEDS AND SITUATION. AT THE SAME TIME THEY ACKNOWLEDGED THE IMPORTANCE OF ENSURING THAT THERE WERE STILL FORMAL SERVICES AVAILABLE IF NEEDED.

RESULTS FROM INTERNATIONAL STUDIES SUGGEST THAT MANY CONSUMERS HAVE BENEFITED FROM THIS MODEL INCLUDING IMPROVED QUALITY OF CARE, GREATER SATISFACTION AND A GREATER SENSE OF SECURITY AND CONTROL. A DEMONSTRATION OF THIS MODEL IN RESPITE CARE IN AUSTRALIA WOULD BE BENEFICIAL IN ORDER TO GAIN A CLEARER UNDERSTANDING OF THE ISSUES

ASSOCIATED WITH IMPLEMENTING SUCH A MODEL. IN MY VIEW, IN THE LONG-TERM, IT WILL BE NECESSARY TO HAVE A MIXED APPROACH TO RESPITE CARE INVOLVING INDIVIDUALISED FUNDING AND GOVERNMENT SUPPORT OF RESPITE SERVICES.

STRATEGIES FOR CARERS

AS I HAVE ALREADY HIGHLIGHTED, INCREASING ACCESS TO APPROPRIATE SERVICES IS ONE WAY TO LOWER CARER BURDEN. THERE ARE, HOWEVER, THINGS THAT CAN BE DONE TO SUPPORT CARERS IN THEIR ROLE.

FOR EXAMPLE, THERE ARE A NUMBER OF STRATEGIES THAT CAN BE UTILISED TO ASSIST WITH BEHAVIOURAL SYMPTOMS OF DEMENTIA. OFTEN CARERS ARE FRUSTRATED AND UNCERTAIN ABOUT HOW TO RESPOND TO ISSUES LIKE AGGRESSION OR WANDERING. THE DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE (DBMAS) HAS JUST DEVELOPED AN EXCELLENT RESOURCE FOR FAMILY CARERS WHICH PROVIDES QUICK TIPS ON HOW TO RESPOND TO BEHAVIOURAL SYMPTOMS OF DEMENTIA.

<http://www.dementiaresearch.org.au/bpsdguide.html>

LOOKING AT THE PHYSICAL DESIGN OF THE HOME CAN ALSO BE IMPORTANT. A WELL PLANNED INTERIOR CAN PROVIDE KEY PROMPTS FOR THE PERSON WITH DEMENTIA AND IMPROVE ACCESSABILITY AND MINIMISE RISKS AS THE INDIVIDUAL NAVIGATES THE HOME ENVIRONMENT. SIMPLE MODIFICATIONS THAT PEOPLE CAN UNDERTAKE INCLUDE REMOVING RUGS, CHAIRS OR CLUTTER WHICH MAY OBSTRUCT WALKWAYS, ENSURING THAT FURNITURE HAS CONTRASTING COLOURS SO THEY CAN EASILY BE SEEN AND REDUCING SHARP EDGES ON FURNITURE CAN MAKE MOVING AROUND THE HOME ENVIRONMENT A LITTLE

EASIER FOR THE PERSON WITH DEMENTIA. A NUMBER OF ASSISTIVE TECHNOLOGIES ARE NOW AVAILABLE FOR USE IN THE HOME ENVIRONMENT GIVING PEACE OF MIND TO CARERS AND GREATER AUTONOMY TO PEOPLE WITH DEMENTIA.

<http://www.enablingenvironments.com.au/>

RECEIVING ASSISTANCE VIA IN HOME SERVICES CAN ALSO GREATLY BENEFIT CARERS AND DELAY THE MOVE INTO RESIDENTIAL CARE FOR THE PERSON WITH DEMENTIA. DOMESTIC SERVICES TO ASSIST WITH TASKS SUCH AS CLEANING, WASHING AND SHOPPING; PERSONAL CARE SERVICES TO ASSIST WITH BATHING, GROOMING AND DRESSING; AND HOME SERVICES AND MODIFICATIONS INCLUDING YARD MAINTENANCE, MINOR REPAIRS AND INSTALLING HAND RAILS AND SHOWER RAILS CAN REDUCE THE NUMBER OF TASKS CARERS NEED TO COMPLETE AROUND THE HOME.

CONCLUSION

YESTERDAY MADELEINE STARR TALKED IN HER POWERFUL PRESENTATION ABOUT THE STRATEGIES EMPLOYED BY CARERS UK IN DEVELOPING THE CONCEPT AND PRACTICE OF CREATING SUPPORTIVE WORKPLACES FOR CARERS.

SHE TALKED, AMONG OTHER THINGS, ABOUT DEVELOPING A CULTURE OF BEING CARER FRIENDLY. A REMINDER THAT SUPPORT AND CARING STARTS AND FINISHES WITH CONNECTION AND THE IMPORTANCE OF RELATIONSHIPS. THE THREE QUESTIONS I HAVE TALKED ABOUT TODAY ARE JUST A FEW OF THE BUILDING BLOCKS WE NEED TO MAKE OUR COMMUNITIES AND ORGANISATIONS, BOTH CORPORATE AND NON GOVERNMENT, DEMENTIA FRIENDLY.

WE ARE SEEKING TO GIVE PEOPLE WITH DEMENTIA A PURPOSE IN LIFE AND SOCIAL ENGAGEMENT. TO REDUCE STIGMA AND SOCIAL ISOLATION AND IN THE PROCESS TO ENRICH THE LIVES OF PEOPLE WITH DEMENTIA AND THEIR FAMILIES. WE ARE AT AN EARLY STAGE IN THIS PROCESS BUT ALREADY WE HAVE COMMUNITIES WHO ARE SIGNING UP TO THE CONCEPT THROUGH LOCAL ACTION GROUPS INCLUDING PEOPLE WITH DEMENTIA AND CARERS.

THE CONCEPT AGAIN IS A SIMPLE ONE AND INVOLVES ENSURING THAT PEOPLE WITH DEMENTIA ARE SUPPORTED TO STAY INVOLVED IN THE COMMUNITY AND IN THE ACTIVITIES THAT THEY ENJOYED BEFORE A DIAGNOSIS. IT IS TOO OFTEN THE CASE THAT AFTER A DIAGNOSIS PEOPLE GIVE UP ON THE THINGS THEY ENJOY FAR BEFORE THEIR COGNITIVE CAPACITY DICTATES THAT THEY MUST.

KATE SWAFFER THE CHAIR OF OUR DEMENTIA ADVISORY GROUP – A GROUP COMPRISED ONLY OF PEOPLE WITH DEMENTIA – TALKS ABOUT PRESCRIBED DISENGAGEMENT. FROM THE TIME OF DIAGNOSIS SHE WAS TOLD TO GIVE UP EMPLOYMENT AND STUDIES. SHE CONTRASTS THAT WITH THE REHABILITATION AND ASSISTANCE THAT WOULD HAVE BEEN AVAILBALE FOR A PERSON WITH A STROKE.

KATE IS NOW WORKING FOR ALZHEIMER'S AUSTRALIA AS A CONSULTANT AS WE ARE DETERMINED THAT OUR DEMENTIA FRIENDLY APPROACH HAS TO INVOLVE PEOPLE WITH DEMENTIA INCLUDING THROUGH DEMENTIA ACTION COMMITTEES AT THE LOCAL LEVEL.

THE CONCEPT AND PRACTICE OF DEMENTIA FRIENDLY COMMUNITIES AND ORGANISATIONS OF COURSE REQUIRES A PRESENTATION IN ITSELF BUT I WANTED TO CLOSE BY EMPHASISING THE IMPORTANCE OF SOCIAL ACTION AS A COMPLEMENT TO GOVERNMENT PROGRAMS AND THOSE OF MY OWN AND OTHER ORGANISATIONS.

DEMENTIA IS AS MUCH A SOCIAL DISEASE AS A MEDICAL ONE AND EVERY INDIVIDUAL AND THEIR FAMILIES WILL HAVE DIFFERENT NEEDS. IN THE END WE SHOULD ADVOCATE, AS PEOPLE WITH DISABILITIES HAVE DONE, FOR A SOCIETY WHICH DIRECTLY ADDRESSES THE CULTURAL AND NEGATIVE ATTITUDES THAT HAVE ATTACHED TO A DIAGNOSIS OF DEMENTIA OVER MANY CENTURIES . THIS HAS TO INCLUDE AN ASSURANCE THAT THE LEGAL RIGHTS OF PEOPLE WITH DEMENTIA ARE PROTECTED AND THAT THEY ARE EMPOWERED TO PARTICIPATE IN OUR SOCIETY TO THE EXTENT THEY ARE ABLE.

IN SHORT WE WANT KEYWORKERS, FLEXIBLE RESPITE AND THE CHOICE OF INDIVIDUALISED FUNDING AND SPECIALIST SERVICES BUT THE STAKEHOLDERS OF ALZHEIMER'S AUSTRALIA ALSO WANT GOVERNMENT AND SOCIETAL SUPPORT FOR ACHIEVING A DEMENTIA FRIENDLY CULTURE.

DISCUSSION POINTS

SOME DISCUSSION POINTS INCLUDE:

- WHAT ARE THE ISSUES YOU HAVE EXPERIENCED IN ACCESSING RESPITE SERVICES?
- WHAT WOULD FACILITATE CONSUMERS IN ACCESSING RESPITE SERVICES?
- IF GIVEN THE OPTION, WOULD YOU OPT TO CASH OUT OF RESPITE?
- WHAT ARE THE ISSUES YOU PERCEIVE IN CASHING OUT RESPITE?